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ABSTRACT

Eleven rehabilitation/independent living counselors in 5 states and the Navajo Nation completed consumer data summary questionnaires on 121 American Indian clients receiving independent living services. The clients lived in Arizona, California, New Mexico, South Dakota, Texas, Colorado, and Utah; 48 were served by the Navajo Nation vocational rehabilitation (VR) project, the only tribal VR project at the time. Counselors supplied demographic information about each consumer, as well as information on referral, disabilities, functional limitations, services provided, outcomes, and closure. Data analysis consisted primarily of a descriptive summary, subdivided by state. Differences in implementation of state plans for independent living created difficulties in data collection. Educational information revealed that 16 percent of clients had 6 years or less of formal education, and half of these had no education at all. The most common goals requested by clients at referral were self-care and mobility. Multiple goals were common. A majority of consumers were not working. The top four independent living services provided to consumers were the four core services required by Title VII of the Rehabilitation Act: information and referral, peer counseling, individual and systems advocacy, and independent living skills training. Service providers rarely had a person specifically assigned to provide outreach services to American Indians. Services were initiated for 66 cases, and closure information was available for 49 cases, of which 77 percent achieved client goals. Includes 28 data tables and the survey questionnaire. (Author/SV)

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This Report is Dedicated

to the Memory of

Ronald Sam

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Summary

This study was conducted to collect and analyze information on the case file characteristics of American Indians who have received independent living services through the state and tribal vocational rehabilitation services and Centers for Independent Living. The research was conducted through the American Indian Rehabilitation Research and Training Center (AIRRTC) at Northern Arizona University.

The AIRRTC research team received 121 consumer data summaries from independent living counselors. Of the 121 consumer data summaries received, 48 were from two Navajo Nation Office of Special Education and Rehabilitative Services independent living counselors. Both of the Navajo Nation independent living counselors' service areas extended into Arizona, New Mexico, Utah, and Colorado. Eleven vocational rehabilitation/independent living counselors from five states (AZ, CA, NM, SD, and TX) completed the consumer data summary questionnaires.

The counselors were asked to supply demographic information about each consumer, as well as referral information, disabilities, functional limitations, services provided, and closure data. Educational information given revealed that one out of every six respondents (16%) had no more than six years of formal education, and half of these had no education at all. Thus, outreach efforts should not assume levels of literacy typical of the population as a whole. The distribution of *Reported Disabilities* varied in unexpected ways: arthritis and rheumatism, and Alzheimer's disease were reported mainly from South Dakota; learning disabilities and emotional/mental disorders were reported mainly from California; various orthopedic disorders and diabetes mellitus were reported mainly from Texas, and paraplegia was reported mainly in Arizona.

The data analysis consisted primarily of a descriptive summary. Where relevant, the results were subdivided by state to make the results more useful to participating statewide independent living councils (SILC). The data analysis also employed other cross-tabulations in order to investigate relationships between variables.

Since Federal legislation mandated that each State develop its own State Plan for Independent Living, considerable variation was found between states as to how independent living (IL) services were implemented. The different ways each state implemented its IL plan made it difficult to establish a uniform data collection instrument for all the states sampled, which in turn affected the reporting of data gathered by this study.

The most common goals in the study sample requested by clients at referral were self-care and mobility. Multiple goals were common. A majority of the consumers reported at referral that they were not working.

The independent living services provided are usually funded by the Title VII of the Rehabilitation Act, and in this Title, the four core services (information and referral, peer counseling, individual and systems advocacy, IL skills training) are required to meet the independent living plans. The top five services provided to American Indian consumers were information and referral, peer counseling, individual and systems advocacy, IL skills training, and prosthesis and other appliances and devices. The top four IL services provided to American Indian consumers were the four core services required by Title VII of the Rehabilitation Act. Independent living service providers rarely had a person specifically assigned to provide outreach services to American Indians on or off reservations. Most American Indian consumers ranged in age from 40 to 64 years of age.

Services were initiated for 66 cases and closure information was available for 49 cases. Goals were achieved for 77% of the clients whose cases were closed.

Follow-up services (including long-term) were either planned or provided in most cases (60%) for which information was provided.

In conclusion, it was much more difficult than expected to collect client case history summaries, and although the sample is not an unbiased sample of all states, tribes and urban American Indians concentrations, it was diverse enough and large enough to have fulfilled the purpose of this study which was to collect information on as many American Indian clients as possible who received IL services. Given the lack of information of this kind in the available literature, this study will help to fill an important gap in information about IL services to this population. When combined with the information from the other activities of this project, it will provide a basis to better understand the current state of development of IL services to American Indians.

It is recommended that IL counselors need to encourage American Indian consumers and tribal service providers to participate in SILC meetings. Participating in SILC meetings could ensure that state plans for independent living include increased services to American Indians with disabilities residing on or near Native lands. Another recommendation is that more comprehensive independent living services should be provided, along with supportive services. Supportive services ensure achieving IL goals due to the severity of the most frequently reported disabilities and multiple disabilities. Training and technical assistance on IL services to counselors affiliated with Centers for Independent Living or independent living programs need to be provided. Additional recommendations are given in the **Conclusions** section of this report.

A Summary of American Indian Independent Living Consumer Data

The primary objective for this report was to collect and analyze information on the case file characteristics of American Indians and Alaska Natives who have received Independent Living (IL) services. The information collected about these consumers was analyzed to answer research questions such as: (a) How many American Indians with severe disabilities are being served by the state Rehabilitation Services Administration (RSA) IL services and the Section 130 IL projects? (b) How successful are the IL/Vocational Rehabilitation (VR) counselors in rehabilitating American Indians with severe disabilities in IL services? (c) If rehabilitated, did the American Indians with severe disabilities benefit from multiple services?

To answer these questions, this report uses data summaries of American Indian client/consumers who have received IL services. Specifically, the research team collected and analyzed case file characteristics of American Indians receiving independent living rehabilitation services in order to answer questions such as the following: (a) How often were the Indian cases closed successfully? (b) How many cases were closed unsuccessfully, and why? (c) Were clients more likely to be referred to IL programs by Indian organizations such as Indian Health Service, or tribal VR programs? (d) If multiple IL services were provided, was there a higher rate of successful closures? (e) Did the reservation resources impact the provision of IL services? (f) What were the most prevalent goals and services that were more likely to be set for Indian clients? (g) What was the most reported closure work status and was it successful or not? (h) Finally, did the IL counselor plan for any follow-up IL services?

Originally, the focus was on the state and tribal IL/VR programs; the centers for independent living (CILs) were to be considered at another time. However, because of the way some state plans for independent living were developed, this distinction proved difficult to maintain, and was changed. Consequently, all of the initial research questions now apply to CILs, as well as to state and tribal IL/VR programs.

At intake, the IL/VR counselor collects basic consumer data, as well as information such as eligibility/planning, setting IL goals, and identifying services provided to closure statuses. An IL Plan (ILP) that tracks progress of the IL goals is also developed. The counselor works together with the client/consumer to develop the ILP, which can be written or verbal. The ILP usually consists of IL services that will either be provided or purchased by the IL program, although sometimes comparable services are identified. The IL/VR counselor identifies functional limitations of the client based on medical information and self-reporting. These identified functional limitations prevent increasing or maintaining the client's IL functioning in their environment, such as their residence, community, or place of employment. The functional limitations then are addressed by overcoming, improving, or correcting them through planned services that will meet the IL goal(s).

Case histories used by the IL/VR counselors with the state and tribal VR agencies are usually summarized in Client Data Reports (CDRs). As the CDRs are reviewed regularly, the counselor can determined if services are on schedule or if the ILP needs to be amended to reflect the current situation.

The original research hypothesis that motivated this study of independent living American Indian client/consumer data summaries was that:

Awareness of culturally relevant IL objectives by the IL/VR counselors will produce greater understanding of American Indians with severe disabilities in meeting their objectives.

The analysis of independent living American Indian client/consumer data constitutes the first step towards developing technical assistance for IL/VR counselors through culturally relevant training workshops, using culturally relevant methods like those described by Clay (1992a) and Brown (1986).

Methodology

At the beginning of the project, a Project Advisory Committee (PAC) was formed that consisted mostly of American Indians and Alaska Natives knowledgeable in IL, and IL liaisons in targeted states (see Appendix A). Throughout the project, the PAC members provided feedback to the research team on research activities relating to IL and culturally relevant research processes. The original methodology for this research had to be modified in order to meet the project objectives; the original research design and modifications leading to the current design are outlined below.

Project Participants

This project was originally intended to focus on three target states (Arizona, New Mexico, and South Dakota) with large populations of American Indians (Table 1) and a high rate of fatalities from motor vehicle accidents. Motor vehicle accidents are often associated with alcohol abuse and poor road conditions, which are commonly found on reservations in these states. After learning about this project, the Texas Rehabilitation Commission contacted the principal investigators, expressing their interest in participating in it. Consequently, Texas was added to the targeted states. The four state vocational rehabilitation agencies (AZ, NM, SD,

and TX) provided a letter of participation and identified an IL specialist as a liaison. The sample was later expanded to include California, North Carolina, and New York, because of their large population of American Indians (see Table 1). In addition, personnel in the California VR system had expressed an interest in the project.

Table 1

American Indian and Alaska Native Population in Targeted States

Rank	State	1990 AI/AN Population
2	California	242,164
3	Arizona	203,527
4	New Mexico	134,355
7	North Carolina	80,155
8	Texas	65,877
9	New York	62,651
11	South Dakota	50,575
17	Colorado	27,776
19	Utah	13,426

(Source: 1990 U. S. Census)

These states represent a diversity of American Indian experience: While three (AZ, NM, SD) have substantial AI/AN populations residing on reservations,

in the others (CA, TX), the AI/AN population is primarily urban. Also, these states incorporate a variety of American Indian cultural situations, from the New Mexico Rio Grande Pueblo villages, to dispersed reservation communities (AZ, SD) and rancherias (CA), to dispersed urban households (CA, TX). Also, the sample reflects the implementation of a State Plan for Independent Living (SPIL) in five states, each with a different approach. This diversity was desired by researchers in order to identify training and technical assistance needs that could be generalized to most states with a substantial AI/AN population.

It was originally anticipated that the state liaisons would help to identify IL/VR counselors within their state VR agencies, and tribal Section 130 VR program counselors who worked with IL programs. These counselors would then identify American Indians with severe disabilities who were currently receiving, had recently received, or wanted to receive services from the state Independent Living Rehabilitation Services (ILRS). Thus, the primary participants in this study were the IL/VR counselors who provided or coordinated IL services for American Indian/Alaska Native consumers. However, another target population was the consumers.

When this project began, only 1 out of 22 tribal Section 130 VR programs across the nation had an IL program--the Navajo Nation Office of Special Education and Rehabilitation Services (OSERS) that covers the Navajo reservation. The Navajo reservation includes parts of the states of Arizona, New Mexico, and Utah. Since most of this reservation falls within two of the target states, this tribal program became an important target for this study.

The original research design targeted only the state VR system; however, PAC members informed researchers that the four target states had different systems of providing IL services. For instance, the New Mexico VR, complying with their SPIL, had subcontracted their Title VII, Part B funds to the CILs in their state. In other

states, Arizona, South Dakota, and Texas, Title VII, Part B funds were used for their ILRS/VR counselors to provide IL services. They also worked in conjunction with the CILs in meeting the SPIL. Consequently, the research design was changed to include IL services provided by the state VR system, the CILs, and other IL programs. Thus, the target populations included:

1. IL/VR, and CIL counselors in states with large American Indian populations as reported by the 1990 U. S. Census, and IL counselors of the Navajo Nation OSERS, a tribal Section 130 VR program.
2. American Indians with severe disabilities who are currently receiving, have received, or want to receive services from the state ILRS, CILs, and IL programs.

Instrumentation

As mentioned earlier, it was anticipated that the states used a uniform Client Data Report (CDR) form to collect information on their IL clients. Consequently, the activities planned for this research involved collecting and analyzing information on the case file characteristics of American Indians who were receiving IL services. Specific activities included:

1. Work with IL/VR counselors to identify American Indian clients who need or are receiving IL services.
2. Obtain copies of CDRs on American Indian clients applying for or receiving IL services. This would be done in a way that protected client confidentiality.
3. Analyze information on CDRs.

The initial draft of the survey instrument was developed using the Arizona CDR as a guideline, which the IL/VR state agency counselors use to record client/consumer information. This survey instrument was developed to make it easier for the IL/VR counselors with the state IL/VR agencies to complete.

However, CIL counselors in New Mexico were not familiar with this form. Furthermore, the computerized tracking systems used by the state IL/VR agencies and Navajo Nation OSERS were not being used by the CILs and ILPs. Thus, researchers developed a Client/Consumer Data Summary (CDS) (Appendix B) form that could be used by all of the above entities. The initial draft of the CDS was reviewed with the PAC members, who were divided about whether to use the term "client" or "consumer." In addition, there was discussion regarding the terminology for services and evidence that there was no standard for reporting information, such as using the same terminologies for specific provider codes and payer codes (Provider codes and payer codes are generally provided for computer billing purposes in most IL/VR programs). After receiving the state plans for IL from target state VR liaisons, the project team reviewed the different terminologies and made appropriate changes. The PAC members in the target states agreed to identify/recruit American Indian clients/consumers who were receiving IL services. The revised CDS form was completed in May, 1994.

Procedure

In May, 1994 a "Q & A," Version 4 for Windows (Symantec, 1993) database for the CDS was created; the data from one Arizona counselor who returned 19 CDSs were entered. The following month, CDS forms were mailed directly to NM CILs and telephone calls were made to remind the other target states in identifying IL/VR counselors with a caseload of American Indians who are receiving IL services. By July, 1994, 37 CDS forms from Arizona and South Dakota were entered in the database and the research team was now considering expanding the sample to other states. This opportunity to expand to other states occurred within the same month when a member of the research team met with a California (CA) VR representative who became interested in the project. This representative volunteered to assist the research team by involving California VR. California VR

had delegated their Title VII, Part B funds to CILs, which is different from the target states of AZ, SD, TX and more similar to NM. A letter of endorsement to CILs requesting for their completion of the CDS forms was sent by California VR personnel. In addition, the research team decided to send CDS forms to the North Carolina (NC) VR, which is ranked the seventh largest population of American Indians (see Table 1) and in which the American Indian Rehabilitation Research and Training Center (AIRRTC) had an established working relationship with the state VR agency.

In August, 1994, the first CDS forms were tabulated; however, analyses were delayed pending responses from two states, TX and NM. In order to increase the responses, follow-up telephone calls to AZ, NM, SD, TX, CA and NC were made. The state of New York Vocational Education Services for Individuals with Disabilities (VESID) was added to gain regional representation. Since a letter of endorsement from a state VR agency has proven to increase responses from state IL/VR counselors, the same procedure was used for the VESID counselors. By September, 1994, a total of 42 CDS forms had been received from AZ, SD, and CA and the following month this increased to a total of 52 CDS forms from AZ, SD, CA, and TX. The research team members were notified by the NY VESID that they would endorse the project and CDS forms were mailed for distribution to CIL counselors in October, 1994.

By November, 1994, 53 CDS forms had been entered into the database. The New Mexico CIL had an identified Pueblo liaison who provided IL services to Pueblo villages; however, the person left, which affected the CDS response rate for New Mexico. In the meantime, additional CDS forms were sent to CILs in North Carolina, New York, and other states. By February, 1995, the project team had a total of 58 CDS forms from AZ, SD, TX, NM and CA.

The research team determined that CDS forms had not been received from Navajo Nation OSERS, a tribal (Section 130) VR project. The research team received a verbal approval from the director of Navajo Nation OSERS to complete CDS forms in their IL offices on April, 1995 in Window Rock, Arizona and Shiprock, New Mexico. This resulted in 48 additional CDS forms (24 in NM, 21 in AZ, 2 in UT and 1 in CO), which helped to increase the sample to 121. After the project team reviewed the overall preliminary report of the analysis, the team noticed discrepancies in IL/VR counselor responses to the CDS forms. Follow-up telephone calls were made to correct the discrepancies; for instance, terms used by AZ IL counselors regarding services provided by them were written as though they were provided by CILs, when they meant that the AZ IL counselors provided the services.

Data Analysis

Information was cross-referenced, with data entered initially and re-entered to make the information more consistent. Data from CDRs "Surveys of IL/VR Counselors, 1994" (such as demographic information, counselor education level, and understanding of American Indian culture) were cross-tabulated with outcome measures, such as reason for closure, and the achievement of goals in self-care, communication, residency, and mobility.

Results

Demographic Information

Age and Sex by State. A total of 11 IL/VR counselors from five states (AZ, CA, NM, SD, and TX) completed the CDS questionnaires. The New Mexico Navajo Nation OSERS IL counselor's service area extended into Utah and Colorado. There were 121 clients/consumers represented in these CDS questionnaires. Of these 121, 48 were from two Navajo Nation OSERS counselors, and 73 were from state ILRS, CILs, and IL programs. Sixty-one were males and fifty-four were females (see

Table 2). The sex of six clients was unknown (left blank). The average age was 45, but there was considerable variation from state to state (see Table 3), which a one-way analysis of variance showed was statistically significant ($F(4,109) = 7.5829$, $p < .0001$). The South Dakota sample had not only the highest mean age (64), but also the highest minimum age (32) and the highest maximum age (88). The New Mexico sample had the youngest mean age (40) and the youngest minimum age (11). Colorado and Utah had a combined total case of 3, which is not statistically relevant in averaging the ages of 2 Utah cases and 1 Colorado case.

Table 2

Sex of Clients by State

	State							
Sex	**AZ**	**CA**	**CO**	**NM**	**SD**	**TX**	**UT**	**Total**
Male	27	11	1	12	6	2	2	61
Female	16	9		15	8	6		54
Unknown	3			1	2			6
Total cases	46	20	1	28	16	8	2	121

Table 3

Age of Clients by State

	State							
	AZ	**CA**	**CO**	**NM**	**SD**	**TX**	**UT**	**Total**
Average age	42	40	28	40	64	56	29	45
Total cases	40	19	1	28	16	8	2	114

Marital Status. Almost half of the consumers were single [(55) 45%], and about one-third [(38) 31%] of these consumers were married (see Table 4). There may be some differences in the marital status categories recorded in each state. For example, the lack of any consumers listed as separated, divorced, or widowed in the SD column may reflect the absence of any consumers in these categories, but it could also mean that the SD VR system does not make these distinctions. Instead, "separated" could be included within "married," and those who are divorced or widowed could be included as "single."

Table 4

Marital Status of Consumers by State

	State							
Marital Status	**AZ**	**CA**	**CO**	**NM**	**SD**	**TX**	**UT**	**Total**
Single	24	9	1	14	5	1	1	55
Married / common law	11	6		5	11	4	1	38
Separated	1	1		2				4
Divorce(d)	5	4		2		1		12
Widow(ed)	4			4		2		10
Unknown	1			1				2
Total	46	20	1	28	16	8	2	121

Number of Dependents and Family Size. CDS information on family size was requested in the closure section, and the number of dependents was requested in the demographic information section on the CDS (see Appendix B). The results are summarized by state in Table 5, showing differences between states in data collection: For example, in Texas, information on both variables was almost always recorded. In Arizona, both were usually recorded. However, in South Dakota, neither was recorded for any of the 16 cases. Because of the small sample sizes, the differences between the means for each state are not significant, although the family size in Texas (maximum = 3) is somewhat smaller than family sizes in Arizona (maximum = 7) and California (maximum = 5).

Table 5

Number of Dependents and Family Size

State	Number of Dependents			Family Size			Cases with no data
	Mean	Standard Deviation	Cases	Mean	Standard Deviation	Cases	
AZ	1.095	1.897	42	2.48	1.759	25	5
CA	.833	1.193	12	3.50	1.732	4	8
CO			1				
NM	1.000	1.378	21				5
SD							16
TX	.500	.756	8	1.80	.837	5	0
UT	1.000	1.414	2				
Total	.965	1.575	86	2.50	1.674	34	34

Residence. As the totals in Table 4 show, the largest number of consumers were from Arizona (46), followed by New Mexico (28), California (20), and South Dakota (16). Within Arizona, the city of residence was given as Window Rock (20), Flagstaff (19), Phoenix (3), or Tucson (2). However, Window Rock sometimes serves as a euphemism for "somewhere on the Arizona part of the Navajo reservation." Most (26) of the NM consumers had their residences listed as Shiprock. California consumers were mostly from Fresno (12) or Bakersfield (5).

Reservation Affiliation/Residence. A reservation affiliation was given for 93 of the cases. The Navajo reservation was best represented, with 19 consumers from Arizona, 27 from New Mexico, Colorado, and Utah. The Pine Ridge (Sioux) and

Hopi reservations were next in frequency, with seven cases each; five were affiliated with the Rosebud (Sioux) reservation, and other reservations had three or fewer cases.

Tribal Affiliation. The majority of consumers were members of the Navajo tribe (n=53) (see Table 6). A large number (26) of these clients was not identified by tribal affiliation for several reasons: (1) California IL/VR counselors do not ask clients for tribal affiliation if identified as American Indian. (2) A Texas counselor reported that the majority of clients don't know their tribal affiliation in the Rio Grande area. The tribal affiliation is more likely to be identified in areas where there are reservations, e.g. El Paso, or IHS facilities. (3) In South Dakota, there are nine "Sioux" reservations representing three tribal/linguistic groups (Lakota, Dakota, and Nakota). People are more likely to identify themselves by their home reservation or tribal/linguistic affiliation, instead of Sioux, whereas IL/VR counselors are likely to combine them.

Primary Language. Information was obtained on the primary language of 95 of the 121 consumers (see Table 7). The largest group was English speakers (n=31), followed by Navajo (n=21). There were 15 bilingual Navajo/English speakers, Navajo usually being written first. Ten Arizona consumers had "AI" written as their primary language.

Educational Level. Sixteen of the 97 cases (13%) for which educational level was known had a maximum of a sixth-grade education and half of these did not attend school. However, 36 (30%) had a 12th grade/high school education, and 17 (14%) had some college education (see Table 8).

Table 6

Tribal Affiliation of Clients by State as Reported by Counselors

Tribe	State							Total
	AZ	CA	CO	NM	SD	TX	UT	
Navajo	26		1	24			2	53
Tribal affiliation unknown	1	17		1	2	5		26
Sioux					14			14
Hopi	8							8
Acoma				3				3
Apache	3							3
Colorado River	2							2
Tigua						2		2
Tohono O'odham (Papago)	2							2
Wintue		2						2
Cherokee		1						1
Choctaw						1		1
Fort Apache	1							1
Fort Mojave	1							1
Pima	1							1
Supai	1							1
Total	46	20	1	28	16	8	2	121

Table 7

Primary Language of Consumers

Primary Language	State							Total
	AZ	CA	CO	NM	SD	TX	UT	
English	5	12		7		5	2	31
Navajo	12			9				21
Navajo/English	7			8				15
"AI"	10							10
Apache	4							4
Hopi	4							4
ASL sign language		2		1				3
Spanish						3		3
Home sign language	1							1
Acoma				1				1
"Non-communicative"				1				1
"None"	1							1
No data	2	6	1	1	16			26
Total	46	20	1	28	16	8	2	121

Table 8

Educational Level

Educational Level	n
Never attended/did not attend school	8
1st grade	2
3rd grade	3
4th grade	1
6th grade	2
8th grade	6
9th grade	4
10th grade	5
11th grade	7
Special education	5
AZ School for the Deaf & Blind	1
12th grade/high school	36
College (1 year)	8
College (2 years)	7
BA degree	2
Unknown or blank	24
Total	121

Referral Information: Reported Disability

The leading disabilities reported at referral are listed in Table 9 in descending frequency were (a) quadriplegia, (b) cardiac and circulatory system conditions, (c) diabetes, (d) paraplegia, (e) deafness or hard of hearing, (f) emotional/mental disorders, (g) blindness or visual impairment, (h) amputation, and (i) arthritis. Multiple disabilities were commonly reported, and the disabilities could often be related (e.g., diabetes and amputation). Frequencies of disabling conditions that appear to be much greater in some states than in other states included:

1. Arthritis and rheumatism	31% of cases in South Dakota; 3% in all other states.
2. Alzheimer's disease	19% of cases in South Dakota; 0% in all other states
3. Learning disability	30% in California; 1% in all other states
4. Emotional/mental disorder	30% in California; 5% in all other states
5. Orthopedic (trunk, back, spina bifida), Orthopedic (lower extremities), except amputations	25% in Texas; 6% in other states
6. Diabetes Mellitus	38% in Texas; 8% in other states
7. Paraplegia	28% in Arizona; 3% in other states

Table 9

Referral Information

Reported Disability	State							
	AZ	CA	NM	SD	TX	UT	CO	Total
Quadriplegia	13	1	7					21
Cardiac and circulatory system conditions	3	3	2	2	2			12
Diabetes mellitus	5	1	1	2	3			12
Paraplegia	10	1	1					12
Deafness/hard of hearing	1	3	5		2			11
Emotional/mental disorders		6	2	1	1	1		11
Blindness/visual impairments	3		6			1		10
Amputation	1	2	1	2	2		1	9
Arthritis (including rheumatism)		2	1	5				8
Learning disability		6	1					7
Orthopedic (trunk, back, spina bifida)	2	1	1		2			6
End-stage renal failure/genito-urinary conditions	2	1	1	1				5
Speech impairments	2		2	1				5
Traumatic brain injury	3		2					5
Orthopedic (lower extremities), except amputations		2	1		2			5
Hemiplegia	3		1					4
Cerebral Palsy	2		1					3
Down's syndrome	2		1					3
Mental retardation	2		1					3
Alcohol abuse/drug abuse	1	2						3
Uses mobility aids	1		2					3
Epilepsy/seizure	1		2					3
Spinal cord injury, level unspecified		2		1				3
Hypothyroidism	2			1				3
Alzheimer				2				2

Table 9

(continued)

Reported Disability	State							
	AZ	CA	NM	SD	TX	UT	CO	Total
Fetal Alcohol Syndrome, diagnosed or suspected			2					2
Respiratory system conditions		1			1			2
Ataxia				1				1
Attention Deficit Disorder		1						1
Bacterial meningitis				1				1
Bell's Palsy	1							1
Cancer		1						1
Cleft palate/cleft lip			1					1
Dwarfism	1							1
Immune deficiency		1						1
"Multiple disabilities"			1					1
Obesity		1						1
Organic brain syndrome			1					1
Orthopedic (all extremities), except amputations					1			1
Orthopedic (upper extremities), except amputations					1			1
Osteogenesis imperfecta			1					1
"Paralyzed from chest down"			1					1
Total disabilities	61	38	49	20	17	2	1	188
Total cases	46	20	28	16	8	2	1	121
Average disabilities per case	1.3	1.9	1.8	1.2	2.1	1.0	1.0	1.5

Referral Information: Referral Sources

The highest referral source (see Table 10) was from Public Health Service (PHS)/ Indian Health Service (IHS) [16 (13%)]. However, 16 (13%) were self-referred. Many unanticipated referral sources, such as self, public welfare agency, and centers for independent living, were identified. On the other hand, several other referral sources [mental hospital (public or private), Social Security Disability Determination, workman's compensation] were not used at all. The referral sources are listed in descending frequency in Table 10.

Institution at Referral. Most clients [94 (78%)] were not in an institution at referral (see Table 11). However, those who were in an institution were most often at medical rehabilitation facilities (MRF) [13 (11%)].

Primary Source of Support. The two most important sources of support of the clients were public funds [93 (68%)] and family/friends [13 (9%)]. Twelve cases reported multiple sources of support. Navajo Nation OSERS identified two cases as having three sources of support and they also had nine cases identifying two sources of support. Arizona ILRS identified one case with two sources of support. Other sources of support are listed in Table 12 in descending frequency.

Table 10

Referral Sources

Referral Source	n	%
Public Health Service/Indian Health Service	16	13%
Self; Self-referral; Self-referred	16	13%
General hospital	10	8%
State VR agency	9	7%
Public welfare agency	8	7%
Centers for Independent Living	8	7%
Tribal VR program	7	6%
Rehabilitation facility	6	5%
Family; Family Member; Daughter; Husband; Parents; Son	6	5%
Other individual	4	3%
TV	4	3%
Other hospital/clinic	4	3%
School for physically or mentally handicapped (public or private)	2	2%
Community mental health center	2	2%
Fresno city college; Public school	2	2%
Walk-In	2	2%
Tribal Community Health Representatives	2	2%
Other chronic/specialized hospital or sanitarium (public or private)	1	1%
Social Security district office	1	1%
Chapter President	1	1%
Tribal Community Health Representative and Aunt	1	1%
Friend	1	1%
Medical supplier	1	1%
Native American Council	1	1%
Navajo Housing Services	1	1%
Navajo Protection & Advocacy	1	1%
Private Agency	1	1%
Rehabilitation Hospital	1	1%
Tribal Health Services	1	1%
Tribal Social Services	1	1%
Total	121	

Table 11

Institution at Referral

Institution type	n	%
None	94	78%
Medical Rehabilitation Facility	13	11%
IHS	2	2%
Other: Group Home (2) County Home (1) Coyote Canyon Rehab Center (1) AZ School for the Deaf & Blind (1) Community Mental Health Ctr(1) Lives at home (1) Not specified (2)	9	7%
Left blank	3	2%
Total	121	100%

Table 12 Primary Source of Support		
Source	**n**	**%**
Public funds (SSI, SSDIB)	93	68%
Family/friends	13	9%
Own income	5	3%
General funds	3	2%
Tribal funds	2	2%
Veteran benefits	1	1%
Workman's compensation	1	1%
Left blank	2	2%
Other	15	12%
Total	135	100%

Goals Set for ILP. The most common goals requested by clients at referral were mobility [40 (33%)] and self-care [36 (30%)] . These and the others are listed in Table 13 in descending frequency. Fifty consumers had requested more than one goal; of these, 14 had 3 goals. The average time in days from "goal set" to "goal achieved" is given in the last column. About one-quarter (24 of 86 = 27%) from Table 13 under "Goal Achieved" of the completed goals took more than 180 days to achieve. The data in Table 13 are broken down by state in Table 14. This shows that Arizona and Texas used a similar system for describing IL goals, and that some consumers had more than one IL goal. The PAC members advised the research

team that states used different systems and state liaisons provided verbal information on their state system. For instance, California, New Mexico, and South Dakota used a different system for describing IL goals. The CILs in California and New Mexico provided IL services and used a different system.

Table 13

Goals Set for ILP

Goal	Set		Goal Achieved	Time (days)				
	n	%	n	0-60	61-120	121-180	>180	Mean (Days)
Mobility	40	33%	23	7	5	2	8	145
Self-care	36	30%	26	10	5	1	7	127
Personal functioning	25	20%	17	3	6	1	5	156
Residential	15	13%	5	2	0	2	1	139
Communication	15	12%	9	3	1	1	2	193
Educational achievement	3	3%	1	1	0	0	0	38
Economic self-sufficiency	3	3%	1	0	0	1	0	179
Social involvement	3	3%	0	0	0	0	0	0
Other Counseling (2) Individual advocacy (2) Motivity (1) Equip/AT (1) Employment (1) Drug/dependency (2) Native healing (1)	10	8%	4	2	1	0	1	81
Total	150		86	28	18	8	24	

Table 14

Number of Completed Goals for Each State

	AZ	CA	CO	NM	SD	TX	Total
Self-care	17	1			4	4	26
Mobility	16		1	1	1	4	23
Personal functioning	15			1		1	17
Communication	7	1				1	9
Residential	2			1		2	5
Educational achievement	1	1					2
Economic self-sufficiency		1					1
Other	3	1					4
Total	61	5	1	3	5	12	87
Total cases per state	46	20	1	28	16	8	

Work Status at Referral. The most frequently reported work status at referral was "not working," [93 (77%)] (see Table 15). Only 4 (3%) were employed in the competitive labor market. Other reported work statuses are shown in Table 15 in descending frequency.

Table 15

Work Status at Referral

Work Status	n	%
Not working	93	77%
Student or trainee	13	11%
Homemaker	5	4%
Competitive labor market	4	3%
Sheltered workshop	2	2%
Unpaid family worker	1	1%
State/Tribal business	0	0
Left blank	3	2%
Total	121	100%

Transportation. When asked about transportation at referral used by clients/consumers, counselors reported that the majority used personal transportation (see Table 16), especially a family vehicle [39 (32%)]. However, just as many [39 (32%)] did not indicate what transportation they used. Twenty-one reported that they used other means of transportation (e.g., a friend's vehicle, tribal transportation, CHR van, medical and rehabilitation van).

Table 16

Transportation at Referral

Transportation	n	%
Family vehicle	39	32%
Own vehicle Wife drives (2)	22	20%
Friend's vehicle	10	8%
Tribal transportation	4	3%
CHR van	4	3%
Medical rehab van	3	2%
Not specified	39	32%
Total	121	100%

Length of Time to Service Initiation

Information was also obtained on the date of application or referral (Status 00/02) and the date when eligibility for services was certified (Status 10). The results (see Table 17) show that it took an average of 108 days to determine eligibility. This is longer than expected. Furthermore, the standard deviation is quite large, which is related to the observation that 27 cases took more than 56 days (8 weeks) to determine eligibility (see Table 17). However, once eligibility was determined, services were initiated in about 12 days, on the average. These results are complicated by the large number of cases in which the dates are the same for the beginning and end of the statuses (Time = "0") (see Table 17). For *Eligibility to*

Table 17

Length of Time (days) Referral/Intake to Service Initiation

	Eligibility	Length of Time (days)						
	Date = "Status 02"	"0"	1-28	29-56	>56	Mean	Std Dev.	n
Intake to Eligibility		24	19	7	27	108	173	77
Eligibility to Service Initiation	18	39	15	7	5	12	34	66

Service Initiation, in 18 cases the eligibility date was marked "Status 02", and the date services initiated field was left blank. "Status 02" is a state vocational rehabilitation case-management number for consumers who have applied for services.

Eligibility Planning: Primary, Secondary, and Tertiary Disabilities

The sample population *that had been determined eligible for independent living services* in Table 18 shows the *Primary Disability*, in Table 19 the *Secondary Disability*, and in Table 20 the *Tertiary Disability*. Ninety-nine total disabilities were reported as primary disability for eligibility planning. The rest of the 22 cases were either in referral status, where information was being evaluated to determine eligibility or put on hold due to lack of funds for services. On the CDS form, the section on "Referral Information" asked for "Reported Disability(ies)" (see Appendix B). This information was compiled in Table 9 by state as "Reported Disability."

Table 18 shows that persons found eligible for services with quadriplegia and paraplegia were the most commonly reported primary disabilities. The total frequency for eligibility for the most commonly reported disability, persons with quadriplegia, was 14 as compared with 21 for reported disability as quadriplegia

Table 18

Primary Disability for Eligibility Planning

Primary Disability	State							
	AZ	CA	NM	SD	TX	UT	CO	Total
Quadriplegia	8	1	4				1	14
Paraplegia	9	1	2					12
Arthritis and/or rheumatism	1	1	3	4				9
Cardiac and circulatory system conditions	1	2		2	2			7
Amputation	1	3		2	1			7
Diabetes mellitus	3		1		2			6
Blindness/visual impairments	3		3					6
Deafness/hard of hearing	1	2			1			4
End-stage renal failure/genito-urinary conditions	1	1	1	1				4
Emotional/mental disorders		1	1	1				3
Learning disability		3						3
Orthopedic (trunk, back, spina bifida)		1			2			3
Traumatic brain injury	2							2
Cerebral Palsy	1		1					2
Alcohol abuse/Drug abuse		2						2
Alzheimer				2				2
Spinal cord injury, level unspecified		1		1				2
Speech impairments				1				1
Down's syndrome			1					1

Table 18

(continued)

	State							
Primary Disability	**AZ**	**CA**	**NM**	**SD**	**TX**	**UT**	**CO**	**Total**
Mental retardation	1							1
Bacterial meningitis				1				1
Cancer		1						1
Debilitation or exertion limitation	1							1
Dwarfism	1							1
Entire body impaired due to disease	1							1
Immune deficiency		1						1
Organic brain syndrome			1					1
Osteogenesis imperfecta			1					1
Total disabilities	35	21	19	15	8	0	1	99
Total cases	46	20	28	16	8	2	1	121
Percent of cases with primary disability known	76	105	68	94	100	0	100	82

(see Table 21). *Seven of the clients with quadriplegia had not yet been determined eligible.*

One explanation for this could be that some consumer's with quadriplegia had not had their reported disability substantiated by medical information or diagnosis. Another possibility is that after the counselor reviewed the medical information, another primary disability was identified that offered functional limitations for which comprehensive independent living services could be

provided that would increase or maintain independent living functioning of the consumer.

On the other hand, the number of persons with paraplegia is the same (12) for both reported (see Table 9) and primary disability (see Table 18), although the distribution of this disability among the states is different (one less in AZ, one more in NM). This was because one NM consumer whose *reported disability* was "confine to a wheelchair" was reclassified in eligibility status as paraplegic, and one AZ consumer whose *reported disability* was "paraplegic uses a wheelchair for mobility prior to developing cholecystitis with ascending cholangitisin" was reclassified as "debilitation or exertion limitation." These serve as examples of how a consumer's disabilities can be re-assessed during the application process. However, quadriplegia and paraplegia were always considered the primary disability, never the secondary or tertiary disability.

Arthritis (often accompanied by rheumatism) increased in frequency from 8 as *reported disability* (see Table 9) to 9 as *primary disability for eligibility* (see Table 18), with a slightly different distribution among states. Of the 12 cases with diabetes mellitus as reported disability, 6 were classified as primary, 8 were classified as secondary, and 2 new cases were discovered that had some other primary disability. Cardiac and circulatory system conditions changed from 12 reported to 7 primary (see Table 18), 8 secondary (see Table 19) and 2 tertiary (see Table 20) disabilities. A similar sorting of reported disability into primary, secondary and tertiary disabilities can be seen with emotional/mental disorders, etc.

When the frequency of reported, primary, secondary, and tertiary disabilities are compared (see Table 21), a number of observations can be made:

- Certain disabilities, notably quadriplegia, paraplegia, amputation, and traumatic brain injury, were always considered primary.

Table 19

Secondary Disability for Eligibility Planning

Secondary Disability	State							
	AZ	CA	NM	SD	TX	UT	CO	Total
Cardiac and circulatory system conditions	2	2	2		2			8
Diabetes mellitus	1	1	1	2	3			8
Emotional/mental disorders		4			1			5
Deafness/hard of hearing			3		1			4
Learning disability		3	1					4
Blindness/visual impairments			2					2
Orthopedic (trunk, back, spina bifida)	1	1						2
Epilepsy/seizure	1	1						2
Arthritis and/or rheumatism		1						1
End-stage renal failure/genito-urinary conditions	1							1
Cancer			1					1
Anemia			1					1
Bell's Palsy	1							1
Hypothyroidism				1				1
Memory loss		1						1
Mental retardation	1							1
Obesity		1						1
Organic brain syndrome		1						1
Orthopedic (lower extremities), except amputations		1						1
Orthopedic, unspecified	1							1
Respiratory system conditions		1						1
Total disabilities	9	18	11	3	7	0	0	48
Total cases	46	20	28	16	8	2	1	121
Percent of cases with secondary disability identified	20	90	39	19	88	0	0	40

Table 20

Tertiary Disability for Eligibility Planning

Tertiary Disability	State							
	AZ	CA	NM	SD	TX	UT	CO	Total
Cardiac and circulatory system conditions			2					2
Emotional/mental disorders		2						2
Deafness/hard of hearing		1						1
End-stage renal failure/genito-urinary conditions					1			1
Anemia			1					1
Ataxia				1				1
Aphasia	1							1
Bronchitis					1			1
Decubitus, right buttocks	1							1
Juvenile Pagets Syndrome (Osteitis Deformans)			1					1
Spinal nerve damage		1						1
Orthopedic, unspecified			1					1
Total disabilities	2	4	5	1	2	0	0	14
Total cases	46	20	28	16	8	2	1	121
Percent of cases with tertiary disability identified	4	20	18	6	25	0	0	12

Table 21
Summary of Disability Information

Disability	Reported at referral	Certified Disabilities			
		Primary	Secondary	Tertiary	Total
Cardiac and circulatory system conditions	12	7	8	2	17
Quadriplegia	21	14			14
Diabetes mellitus	12	6	8		14
Paraplegia	12	12			12
Emotional/mental disorders	11	3	5	2	10
Arthritis (incl. rheumatism)	8	9	1		10
Deafness/hard of hearing	11	4	4	1	9
Blindness/visual impairments	10	6	2		8
Amputation	9	7			7
Learning Disability	7	3	4		7
End-Stage Renal Failure/genito-urinary conditions	6	4	1	1	6
Orthopedic (Trunk, Back, Spina Bifida)	6	3	2		5
Traumatic Brain Injury	5	2			2
Cerebral Palsy	3	2			2
Mental retardation	3	1	1		2
Alcohol abuse/Drug abuse	3	2			2
Alzheimer	3	2			2
Epilepsy/Seizure	3		2		2
Spinal cord injury, level unspecified	3	2			2
Cancer	1	1	1		2
Organic brain syndrome	1	1	1		2
Anemia			1	1	2
Orthopedic, unspecified			1	1	2
Speech impairments	5	1			1
Down's syndrome	3	1			1
Bacterial meningitis	1	1			1
Dwarfism	1	1			1
Immune deficiency	1	1			1
Osteogenesis imperfecta	1	1			1
Debilitation or exertion limitation		1			1
Entire Body impaired due to disease		1			1

Table 21

(continued)

Disability	Reported at referral	Certified Disabilities			
		Primary	Secondary	Tertiary	Total
Orthopedic (lower extremities), except amputations	5		1		1
Hypothyroidism	3		1		1
Respiratory system conditions	2		1		1
Bell's Palsy	1		1		1
Obesity	1		1		1
Memory loss			1		1
Ataxia	1			1	1
Aphasia				1	1
Bronchitis				1	1
Decubitus, right buttocks				1	1
Juvenile Pagets Syndrome (Osteitis Deformans)				1	1
Spinal nerve damage				1	1
Total disabilities	175	99	48	14	161

- Other disabilities that were almost always considered primary include arthritis (including rheumatism) and blindness/visual impairment.
- A secondary disability was usually identified in California (90%) and Texas (88%), but was less often identified in New Mexico (39%), Arizona (20%), and South Dakota (19%).
- Some disabilities were more often considered secondary or tertiary than primary (e.g., cardiac and circulatory system conditions, diabetes mellitus, emotional/mental disorders, learning disability, epilepsy/seizures).
- Some disabilities that were not apparent at application may be diagnosed during client evaluation as a major disability. The most frequent examples are cardiac

and circulatory system conditions, diabetes mellitus, and arthritis (including rheumatism).

- Some reported disabilities in this sample were always re-evaluated and changed during client evaluation, although it is possible that some of these clients were still in diagnostic services, and did not yet have a recognized primary disability. These reported disabilities included hemiplegia; uses mobility aids; Fetal Alcohol Syndrome, diagnosed or suspected; Attention Deficit Disorder; cleft palate/cleft lip; "multiple disabilities;" orthopedic (all extremities), except amputations; orthopedic (upper extremities), except amputations; "paralyzed from chest down."
- One hundred ninety-five reported disabilities translated into a total of 161 primary, secondary, and tertiary disabilities.

Functional Limitations

Counselors were asked to identify known and corrected functional limitations of clients. The majority reported mobility [69 (57%)] as the most served, with 45 (65%) corrected. On average, about two functional limitations per person were identified. The limitations "Known" and "Corrected" are listed in Table 22 in descending order of "Known" frequency.

Services Provided

The top five services provided to American Indians with disabilities were (a) information and referral, (b) peer counseling, (c) individual and systems advocacy, (d) IL skills training, and (e) prostheses and other appliances and devices. The other services provided are listed in descending order of frequency in Table 23. As expected, the majority of the four independent living core services (Information &

Table 22

Limitations Known and Corrected

Limitations	Known	% Known (of 121)	Corrected	% Corrected
Mobility	69	57%	45	65%
Motivity	19	16%	14	74%
Communications	19	16%	9	47%
Restricted environment	18	15%	7	39%
Mental	14	11%	4	29%
Pain	9	7%	4	44%
Sensory	8	7%	3	38%
Dysfunctional behavior	7	6%	5	71%
Debilitation/exertion	7	6%	6	86%
Substance dependency	4	3%	1	25%
Educational skills (English)	4	3%	1	25%
Uncertain prognosis	3	2%	3	100%
Invisible	2	2%	0	0
Atypical appearance	1	1%	1	100%
Total	184(121)		103	

Table 23

Services *Provided*

	Services *Provided* by:						
Service	**ILRS**	**ILC**	**MED**	**IHS**	**HOS**	**Other**	**Total**
Information & Referral	29	25		2			56
Peer counseling	25	17				AZ RSA Rural Blind srvs	43
Individual & systems advocacy	22	11					33
IL skills training	22	8				AZ RSA Rural Blind srvs Private (2)	33
Prostheses & other appliances & devices	8		19	1	1	Medical Rehab Facility	30
Housing related services	6	7		1		Private (4) Tribe Navajo Housing services Navajo Veterans program	21
Personal assistance/ Attendant care		3	1	1	2	Dept. of Health srvs (2) Winslow Counseling ctr (2)	11
Mobility training	6	1		1		Private Public Schools AZ RSA Rural Blind srvs	11
Therapeutic treatment (e.g., PT, OT, or ST)	2				4	Medicare Medical Rehab Facility	8
Psych. counseling or Psychotherapy	1			5	1	Winslow Counseling Ctr	8
Transportation	3				1	Private (2) Winslow Counseling Ctr(2)	8

Table 23

(continued)

	Services *Provided* by:						
Service	**ILRS**	**ILC**	**MED**	**IHS**	**HOS**	**Other**	**Total**
Rehabilitation technology	5	1			1		7
Education & training for community living	2			3		Community College Winslow Counseling Ctr	7
Interpreter and reader services	1	2				AZ RSA Rural Blind srvs Public Library	5
Consumer Information programs	1		1			Counseling Center	3
Physical rehabilitation					3	Medicare	4
Supported living					1	Home Health Agency	2
Social/recreational services				1		Home Health Agency	2
Surveys and directories						State	1
Community awareness programs or activities	1						1
Other Wheelchair (7) IL devices (6) Wheelchair ramps (6) etc.	13	3	9			Private (2) Navajo Housing srvs. (2) Beclabito Chapter House Vocational Rehabilitation	31
Total	147	78	30	15	14		

ILRS - Independent Living Rehabilitation Services
ILC - Independent Living Center
MED - Medical Equipment Dealer
IHS - Indian Health Service
HOS - Hospital

Referral, Independent Living skills training, peer counseling, and individual & systems advocacy) were provided by independent living rehabilitation services [ILRS] of the state VR agency or a center for independent living [CIL]. Prostheses and other appliances and devices were primarily provided by medical equipment dealers [MED]. Respondents reflected various interpretations on "services provided" such as prosthesis and other appliances and devices, housing related services, and therapeutic training. Vendors and IL service providers were identified as providing services. The most common "other" services provided were wheelchairs, independent living devices, and wheelchair ramps. The most common service providers not already listed were Indian Health Service and hospitals. Other service providers are listed in Table 23 under the heading "Other." Usually these services are case managed or coordinated by the independent living counselor. The independent living counselor then ensures that services provided by the other entities are completed to the satisfaction of the consumer.

As seen in Table 24, the majority of services were paid by ILRS (195), followed by the ILCs (69). However, Indian Health Service was also a major payer, especially for psychological counseling or psychotherapy (5 cases).

Closure

Services were initiated for 66 cases (see Table 17). Closure information was available for 49 cases. Seventy-one percent of these 49 were not working at closure and 8% were closed in a competitive labor market (see Table 25). At closure, the economic need was determined by the IL/VR counselor by reviewing monthly/annual income and comparing it with a predetermined dollar amount set by a state agency. Thirty of the consumers were considered to be below poverty level. Two consumers did not meet economic need. There was no information on economical need for 83 cases.

Table 24

Services *Paid*

Service	Services *Paid* by:						Total
	ILRS	ILC	IHS	MED	MCARE	Other	
Information & Referral	29	14	2			Vocational Rehabilitation	46
Peer counseling	26	15				Vocational Rehabilitation	42
IL skills training	25	8					33
Individual & systems advocacy	22	11				State	34
Prostheses and other appliances and devices	25		1	1	1	Navajo Handicapable Trust Funds AZ Health Care Cost Containment System	30
Housing related services	9	2	1			Navajo Handicapable Trust Funds Navajo Veterans Program	14
Mobility training	8	1	1			Public Schools	11
Personal assistance/ Attendant care	2	2	1	1	1	TX Dept. of Health Services (2)	9
Psych. counseling or Psychotherapy	1		5			Winslow Counseling Ctr Hospital	8
Therapeutic treatment (e.g., PT, OT, or ST)	4		1		1	Private Insurance	7
Rehab. technology	6						6
Education & training for community living	3		3			Church	7
Transportation	5				1	Private	7

Table 24
(continued)

Service	Services *Paid* by: ILRS	ILC	IHS	MED	MCARE	Other	Total
Interpreter and reader services	2					Vocational Rehabilitation Public Library	4
Physical rehabilitation			1		2	Hospital	4
Consumer Info progs.	2			1			3
Supported living					1	Medicaid	2
Social/rec. services			1			Home Health Agency	2
Community awareness programs or activities	1						1
Surveys and directories	1						1
Other Wheelchair (7) IL devices (6) Wheelchair ramps (6) etc.	24	3		3	1	Navajo Housing Services (2) Public Employee Project Vocational Rehabilitation	35
Total	195	69	17	6	8		

Of the 121 cases, 26 (21%) were in applicant status, and 49 (40%) were still active cases. Of the forty-nine cases that had closed, 36 of the cases were closed as successful (IL goals met) (see Table 26). Nine cases were not closed successfully and for four, closure information on "closure reason" were listed as "other." One case reported 2 closure reasons (failure to maintain contact and failure to participate).

Fourteen cases were reported as "unknown" or "unsure" about consumer satisfaction at closure (see Table 27). When there was information, most of the

Table 25

Work Status at Closure

Work Status	n	%
Not working	35	71%
Competitive labor market	*4	8%
Homemaker	3	6%
Student	3	6%
Sheltered workshop	2	4%
Deceased	2	4%
Total	49	100%

* One case had closure reason completed as "IL goals met" and work status at closure was left blank. At referral, this case was checked that the person was working in competitive employment.

Table 26

Closure Reason

Closure Reason	n	%
Successful: IL goals met	36	72%
Failure to maintain contact	5	10%
Failure to participate	2	4%
Deceased	2	4%
Institutionalized	1	2%
Other	4	8%
Total cases	49*	100%

* 1 case file had two closure reasons

Table 27 Consumer Satisfaction at Closure		
Consumer Satisfaction	**n**	%
Very Satisfied	17	35%
Satisfied	17	35%
Unknown	10	20%
Unsure	4	8%
Not Satisfied	1	2%
Total	49	100%

clients were either satisfied [17 (35%)] or very satisfied [17 (35%)] at case closure, while only one consumer was not satisfied.

There was no information on follow-up services (see Table 28) for seven closed cases (14%). Of the 42 cases with information, follow-up services were *planned* for 7 consumers, *provided* for 13 consumers, and there were *long-term follow-up* services for 5 consumers. In other words, follow-up services (including long term) were either planned or provided in most [25 (60%)] cases for which information was provided.

Table 28

Follow-up Services After Closure

Follow-up Services	Yes	No	Other	n	%
Provided	13	5		18	37%
Planned	7	6	1	14	29%
Long term follow-up services	5	5		10	20%
Left blank				7	14%
Total closed cases	25	16	1	49	100%

Discussion

Presently, there is much information on the lack of outreach services and the need for culturally relevant vocational rehabilitation services to American Indians with disabilities (Marshall, 1994; Schacht, Morris, & Gaseoma, 1994; Morgan & O'Connell, 1987; Marshall, Martin, & Johnson, 1990). In contrast, there is limited information on the independent living needs of American Indians with disabilities (Sanderson, Schacht, & Dapcic, 1995; Clay, 1992a; Clay, 1992b) and limited information on the state of independent living services to American Indians and Alaska Natives residing on and off Indian lands.

The consumer data summary questionnaires revealed some findings that could provide insight into the current state of independent living services to American Indians. For instance, the three entities that are well known for providing independent living services to consumers (Independent Living Rehabilitation Services, Centers for Independent Living, and Independent Living Programs) are inconsistent in data collection during intake, service provision,

outreach services, and recording closure information. In the Rehabilitation Act of 1973 as amended in 1992 (PL 102-569) regarding Title VII, an attempt was made to address collaboration between the three entities:

> The plan shall provide for the review and revision of the plan, not less than once every 3 years, to ensure the existence of appropriate, financial support and coordination, and other assistance to appropriately address, on a statewide and comprehensive basis, need in the State for:
>
> (A) the provision of State Independent Living Services;
>
> (B) the development and support of a statewide network of centers for independent living; and
>
> (C) working relationships between programs providing:
>
> (i) independent living services and independent living centers; and
>
> (ii) the vocational rehabilitation program established under Title I independent living services and independent living centers; and the vocational rehabilitation program established under Title I, and other programs providing services for individuals with disabilities (106 STAT. 4444).

The [state] plan shall set forth the steps that will be taken to maximize the cooperation, coordination, and working relationships among-

> (1) the independent living rehabilitation service program, the Statewide Independent Living Council, and centers for independent living; and
>
> (2) the designated State unit, other State agencies represented on such Council, other councils, that address the needs of specific disability populations

and issues, and other public and private entities

determined to be appropriate by the Council (106 STAT. 4445).

This needs to be explored further to increase the effort for collaboration between the three entities. Five State Plans for Independent Living (SPILs) were reviewed. The five SPILS reviewed affirmed that steps will be made to provide outreach services to populations, including unserved or underserved populations in urban and rural areas. Three SPILs identified plans and strategies for outreach services to American Indian communities. The three SPILs that identified these plans submitted more Consumer Data Summaries than the other states that did not specifically identify strategies for outreach IL services to American Indians. The SPILS reviewed did not coordinate their plans with the Navajo Nation OSERS IL program. Most independent living entities expressed concern that there needs to be some training on how to provide outreach services to American Indians on and off Indian lands and what cultural factors to consider.

The majority of the respondents who supplied consumer data summaries for this project came from state VR agencies that had an Independent Living Rehabilitation Service (ILRS), which includes a Section 130 VR program. Some possible explanations are that the ILRS programs were more likely to complete the questionnaires, which meant that IL services to American Indians was/were provided by them. Secondly, the state ILRS programs have more counselors assigned to a larger geographical service area to provide IL services to consumers than CILs. Thirdly, the ILRS programs have resources for travel such as state/tribal vehicles, support personnel, and greater access to training needs on IL.

Few centers for independent living responded to the questionnaire. Few of the CILs contacted had a person specifically assigned to provide outreach services to American Indians on or off reservations. The nine states included in the study are ranked in the top 19 states with a high population of American Indians according to

the U. S. Census. Due to limited resources and personnel, an attempt to provide IL services on or off reservations appeared to not be a priority. The assumption that American Indians with significant disabilities are able to visit a distant CIL for services seems dubious and needs to be explored further by statewide independent living councils.

Most American Indian consumers served by the respondents ranged from 40 to 64 years of age. The frequencies of reported disabilities appear to be much greater than expected in that most cases of arthritis, rheumatism, and Alzheimer's disease were reported from South Dakota, and most cases of orthopedic (trunk, back, spina bifida) and orthopedic (lower extremities) and diabetes mellitus were reported from Texas (see page 18). The following information corresponds to the 40 to 64 age group served most often: primary source of support reported most often was public funds (SSI, SSDI) and family/friends; the most common work status at referral was "not working"; and at eligibility planning, the secondary and tertiary disabilities reported most often were cardiac and circulatory system conditions. The educational level of this group was sixth grade. The IL counselors on the Navajo reservation were more likely to leave the educational level blank or record "unknown."

A review of the CDS forms showed that most Navajo consumers were between 60 and 80. Two were recorded as "did not attend school" and their ages were 84 and 67. South Dakota respondents did not complete the educational level on their CDS questionnaires, which may mean that the liaison completing the questionnaire did not have that specific information available. Perhaps due to the geriatric age of the majority of the consumers served, this information was unknown, or this information was not asked. Because of the average educational level, there would be some reading difficulties; thus, outreach services to this population and age group require careful planning for developing brochures with regard to terminologies, acronyms, and content. The educational skills (English)

level was not addressed sufficiently by the counselors when it was considered one of the goals in the independent living plan.

At referral status, questions were asked about number of dependents and at closure status family size. There were some cases that reported two dependents at referral and at closure "four family size," which left it up for interpretation. Perhaps one of the family members was not counted as a dependent, the family size at referral increased at closure status, or the other person, possibly a spouse, was considered not a dependent because she/he was working. In three cases, a family of four had no dependents; in another case, a family of five had no dependents. Was the word "dependents" used differently in these cases, or were extended family members residing in the household? The questionnaire should have asked for number of dependents and family size at both referral and closure statuses.

Information on "institution at referral" revealed that most referrals came from Public Health Services or Indian Health Service, general hospitals, state VR agency, and tribal VR programs. Other referral sources were identified, such as public welfare agency, independent living centers, Native American Council, and Navajo Protection and Advocacy. This suggests that various sources are somewhat aware of independent living services. In particular, there was one reservation community rehabilitation facility that was identified as a referral source, the Coyote Canyon Rehabilitation Center in Brimhall, New Mexico. There were no nursing homes listed as referral sources, which may mean that counselors do not go to nursing homes for outreach services. Or, perhaps nursing homes are not considered a viable referral source for increasing independent living, because of the setting, which has support personnel such as, nurses, nurses aides, orderlies, cooks, janitors, housekeepers, physical therapists, occupational therapists, or speech therapists.

There were 21 consumers who relied on other people or agencies for transportation (friend's vehicle, tribal transportation, community health representative van, medical rehabilitation van). This may correspond to the average age of 45, which is the group that was most often served. At least 22 reported that they owned a vehicle and of that, two reported that their wife drives. Of the two that reported that their wife drives, one was reported as a person who is blind and the other as a person with quadriplegia. The consumer who is blind was provided with an IL skills training and healing ceremony and the consumer who is a quadriplegic was provided with housing-related services. The majority of the respondents left transportation at referral reported as unknown or blank. In addition to sending questionnaires, a copy of the initial interviews should have been requested to review relevant information.

Limitations of this Study

Results of this questionnaire should be interpreted with caution for several reasons. First, the survey sample is limited to seven states (AZ, CA, CO, NM, SD, TX, UT). Within these states, identified vocational rehabilitation and independent living counselors who have provided or are providing independent living services to American Indians were asked to complete the consumer data summary questionnaire. Thus, information may not be representative to other states. Second, the sample is small. The researchers initially targeted state VR agencies with Independent Living Rehabilitation Services (ILRS) and Centers for Independent Living (CILs) in Arizona, New Mexico, Texas, and South Dakota. However, an attempt was made to expand the sample by including a Section 130 vocational rehabilitation program that had an ILRS program, the Navajo Nation Office of Special Education and Rehabilitation Services (service area includes AZ, NM, CO, & UT) and CILs in California. Thus, data is needed from other states to form a larger sample to determine generalizability of the current findings. Third,

the research team thought that using the Arizona ILRS's program Client Data Report (CDR) form as a guideline in developing the consumer data summary questionnaire would be easier for the IL counselors to complete. We learned that the CIL counselors were not familiar with this form. Thus, questionnaires have to be developed in coordination with CILs, ILRS, and independent living programs to ensure that an understanding of terminologies, program objectives, and goals are understood. Fourth, most service providers are not required to identify tribal affiliations of American Indian consumers and some American Indian preferences for tribal affiliations are not their federal or state recognized tribal names. Since the questionnaires were already sent to states that identify consumers as "American Indian," and don't identify tribal affiliations, for example, Navajo or Lakota Indian, the researchers had to accept the questionnaire as is, which leaves some questionable information on what types of tribes are being served in those states.

Conclusions

From February, 1994 to June, 1995, the research team collected 121 Client/Consumer Data Summaries from seven states (AZ, CA, CO, NM, TX, SD, UT). Permission was sought from eight additional states (NY, OK, NC, AK, MN, WA, OK, MI) to send CDS questionnaires. Endorsements were granted from state vocational rehabilitation agencies in NY and OK; however, no data were provided by these two states. The remaining states did not participate due to various reasons. The research questions that formed the basis of this study uncovered results that can be used by the research team in planning a research-dissemination project for training and technical assistance to the Statewide Independent Living Councils, centers for independent living, and independent living programs.

The total number of American Indians with disabilities that were provided independent living services are as follows:

1) 48 cases were reported by state vocational rehabilitation independent living programs commonly referred to as independent living rehabilitation services.
2) 25 cases were reported by centers for independent living.
3) 48 cases were reported by tribal vocational rehabilitation program's independent living program.

The Navajo Nation OSERS is the only (Section 130) tribal vocational rehabilitation program that provided independent living services to Navajo people with disabilities. By reviewing the number of cases served by the three agencies, it appears that having an independent living program within a tribal vocational rehabilitation program increases access for independent living services for residents residing on reservations.

The IL/VR counselors successfully achieved/met 36 independent living goals. Eleven goals were not achieved/met for various reasons (see Table 27). Twenty-six Navajo Nation OSERS IL cases were in eligibility status and the rest (49) were in active status; in other words, independent living services were still being provided.

The independent living Client/Consumer Data Summary represents an attempt to determine the current state of independent living services to American Indians with significant disabilities by gathering information from state VR agencies with independent living rehabilitation services, centers for independent living, and independent living programs. To summarize, American Indian consumers were most likely to be referred to independent living services by organizations that provide services to American Indians, such as the Indian Health Service, tribal vocational rehabilitation programs, and community health representatives. These entities need to collaborate more closely on service planning and service provision. The age group that needs to be targeted for services are the young adults with significant disabilities. Providing services to a younger population may also

increase the reading level and closure status to "competitive labor market". The CDS left some unanswered questions, for instance, "referred to vocational rehabilitation" should have been included under the category of work status at closure.

Recommendations

This report concludes with 12 recommendations based on the results of the study.

1. Independent living counselors need to encourage American Indian consumers and tribal services providers, like the American Indian Vocational Rehabilitation Program, to participate in the Statewide Independent Living Council (SILC) and to educate the SILC on the need for IL services in Indian communities.

2. Services offered by the independent living rehabilitation services, centers for independent living, and independent living programs need to be coordinated and disseminated to American Indians with disabilities and service organizations that provide services to American Indian people.

3. Young American Indians with significant disabilities appear to be underserved by independent living services. This indicates a need to provide information about independent living services to counselors associated with high schools, community colleges (tribal/public), and universities.

4. The lack of resources for some centers for independent living plays a significant role in limiting outreach services to American Indians and can be addressed either by the state unit or federal government by providing more funding to CILs where significant American Indian populations are, funding CILs and/or satellite offices in Indian communities, or establishing a cooperative agreement with Indian nations to provide independent living services.

5. Spending some time working on gaining rapport with the American Indian consumers (such as inquiring about tribal affiliations, clan memberships, and which reservations or Pueblo villages the consumer is from) could enhance the interest of American Indian consumers in independent living services and improve outcomes.

6. Counselors should be sensitive to the American Indian consumer's primary language. If the consumer is not fluent in English, they may fail to understand important components of their independent living plan. In some cases, the services of an interpreter may be needed.

7. Because American Indians with mental/emotional illnesses appear to be underserved, which may be due to the reluctance to discuss mental or emotional illnesses due to cultural taboos or ignorance, counselors need to take more time to educate family members, tribal service providers, and tribal leaders about the nature of mental illness to dispel preconceptions about it and to encourage referrals.

8. Independent living counselors should provide more comprehensive services in addition to the four mandated services (peer counseling, information and referral, advocacy, and independent living skills training). For example, since the American Indian consumers frequently reported multiple disabilities and spinal cord injuries as their primary disability at referral status, these clients may need more mobility training, therapeutic treatment, or transportation.

9. The American Indian vocational rehabilitation programs should be provided with independent living funds from Title VII of the Rehabilitation Act. It was clear that the Navajo Nation OSERS Independent Living Rehabilitation Services program provided more independent living services to Navajo consumers on their reservation than other entities.

10. Since SILC meetings are open to the public, an attempt should be made to conduct them in various rural and American Indian community settings. Permission should be sought from tribal officials to conduct and coordinate these meetings with an identified tribal liaison.

11. Regional Rehabilitation Continuing Education Programs should provide training and technical assistance on independent living services to counselors affiliated with ILRS, centers for independent living, independent living programs, and American Indian vocational rehabilitation programs. Also, capacity building on writing grants for independent living services should be provided to consumers,

American Indian tribes, and American Indian vocational rehabilitation programs.

12. The IL counselors should provide more of the supportive services which are identified through an evaluation of independent living needs to ensure achievement of IL goals due to the severity of the most frequently reported disabilities and multiple disabilities. Supportive services could include addressing transportation issues, housing-related services, personal assistance/attendant care, and assistive aids and devices.

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Appendix A

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Appendix B

Independent Living American Indian Client/Consumer Data Summary

May 2, 1994

Independent Living American Indian Client/Consumer Data Summary

Project R-40

American Indian Rehabilitation Research and Training Center

Northern Arizona University

Program Information

Name of program supplying client data summary

_____

Contact person

Name _____

Address _____

City _____

State _____ Zip _____

Telephone (____) _____

Demographic information

Arbitrary client ID _____

Sex ☐ M ☐ F Age at intake _____

Marital status _____

Number of dependents _____

Residence: State _____

City _____

Reservation _____

Primary language _____

Tribal affiliation _____

Highest grade completed _____

Referral Information

Referral/Intake date _____

Reported Disability (ies)

_____

_____

Referral Sources(s)

- ☐ School for physically or mentally handicapped (public or private)
- ☐ Mental hospital (public or private)
- ☐ Community Mental Health Center
- ☐ General hospital
- ☐ Public Health Service/IHS
- ☐ Other hospital/clinic
- ☐ Rehabilitation facility
- ☐ Other chronic/specialized hospital or sanitarium (public or private)
- ☐ Social Security Disability Determination Unit
- ☐ Social Security District Office
- ☐ Workman's Compensation
- ☐ State VR agency
- ☐ Tribal VR program
- ☐ Other _____

Institution at Referral

- ☐ None
- ☐ IHS
- ☐ Medical Rehab Facility
- ☐ Other _____

Primary Source of Support

- ☐ Own income/savings
- ☐ Family and friends
- ☐ Veteran's benefits
- ☐ Public funds (SSI, SSDIB, etc.)
- ☐ General funds (not federal)
- ☐ Workman's Compensation
- ☐ Tribal funds
- ☐ Insurance
- ☐ Other _____

Services Requested by Client/Consumer

- ☐ Self-care
- ☐ Mobility
- ☐ Communication
- ☐ Residential
- ☐ Other _____

CLIENT/CONSUMER DATA SUMMARY

REFERRAL INFORMATION (CONTINUED)

Work Status at Referral

- ☐ Competitive labor market
- ☐ Sheltered workshop
- ☐ State/Tribal business
- ☐ Homemaker
- ☐ Unpaid family worker
- ☐ Student or trainee
- ☐ Not working

Transportation at Referral

- ☐ Own vehicle
- ☐ Family vehicle
- ☐ Friend's vehicle
- ☐ Tribal transportation
- ☐ CHR van
- ☐ Medical Rehab van
- ☐ Other _____

ELIGIBILITY/PLANNING

Date eligibility certified _____

Date services initiated _____

Primary disability _____

Secondary disability _____

Tertiary disability _____

Functional Limitations

	Known	Corrected		Known	Corrected
Mobility	☐	☐	Substance dependency	☐	☐
Communications	☐	☐	Dysfunctional behavior	☐	☐
Sensory	☐	☐	Uncertain prognosis	☐	☐
Mental	☐	☐	Atypical appearance	☐	☐
Pain	☐	☐	Restricted environment	☐	☐
Invisible	☐	☐	Debilitation/exertion	☐	☐
Motivity	☐	☐	Educational skills (English)	☐	☐
Consciousness	☐	☐	Other _____	☐	☐
			_____	☐	☐

GOALS

		Date		Date
Self care	☐ set	_____	☐ acheived	_____
Communication	☐ set	_____	☐ acheived	_____
Personal functioning	☐ set	_____	☐ acheived	_____
Educational achievement	☐ set	_____	☐ acheived	_____
Social involvement	☐ set	_____	☐ acheived	_____
Economic self-sufficiency	☐ set	_____	☐ acheived	_____
Residential	☐ set	_____	☐ acheived	_____
Mobility	☐ set	_____	☐ acheived	_____
Other _____	☐ set	_____	☐ acheived	_____

Was a rehab engineer used for functional assessment? ☐ Yes ☐ No

CLIENT DATA SUMMARY

SERVICES PROVIDED

Please use the letter codes shown at the bottom of the page to indicate providers and/or payors

Service	Provided by	Paid by
Information and referral		
IL skills training		
Peer counseling		
Individual and systems advocacy		
Psychological counseling or psychotherapy		
Housing related services		
Rehabilitation technology		
Mobility training		
Interpreter and reader services		
Personal assistance/attendant care		
Surveys and directories*		
Consumer information programs		
Education and training for community living		
Supported living		
Transportation		
Physical rehabilitation		
Therapeutic treatment (e.g. PT, OT, or speech therapy)		
Prostheses and other appliances and devices		
Social/recreational services		
Training for youths		
Services for children		
Services under other federal, state or local programs		
Preventive services		
Community awareness programs/activities		
Other _____		

* Activities to identify appropriate housing, recreation opportunities, accessible transportation, and other support services

Provider Codes	
HHA	Home Health Agency
HOS	Hospital
IHS	Indian Health Service
ILC	IL Center
MED	Medical Equipment Dealer
MD	Physician
MRF	Medical Rehab Facility
PCS	Private Counseling Service
RX	Pharmacy
USPS	Public Schools

Payer Codes	
IDEA	Individuals with Disabilities Education Act
ILC	IL Center
MCAID	Medicaid
MCARE	Medicare
PINS	Private Insurance
PRIV	Private

(If other, write it in)

CLIENT DATA SUMMARY

CLOSURE

Please enclose a copy of your economic need chart, if any

Economic need met? ☐ Yes ☐ No Family size _____

Were goals achieved? ☐ Yes ☐ No Closure date _____

Work Status at Closure

- ☐ Competitive labor market
- ☐ Sheltered workshop
- ☐ State/Tribal business
- ☐ Homemaker
- ☐ Unpaid family worker
- ☐ Student or trainee
- ☐ Not working

Closure Reason

- ☐ Successful: IL goals met
- ☐ Failure to maintain contact
- ☐ Failure to participate
- ☐ Failure to follow IL plan
- ☐ Unable to achieve IL goals
- ☐ Deterioration of disability
- ☐ Institutionalized
- ☐ Deceased
- ☐ Other _____

Consumer Satisfaction at Closure

- ☐ Very satisfied
- ☐ Satisfied
- ☐ Unsure
- ☐ Not satisfied
- ☐ Unknown

(Please provide info on how your agency evaluates consumer satisfaction)

Follow-up Services

- ☐ Planned
- ☐ Provided
- ☐ Long term follow-up services

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